



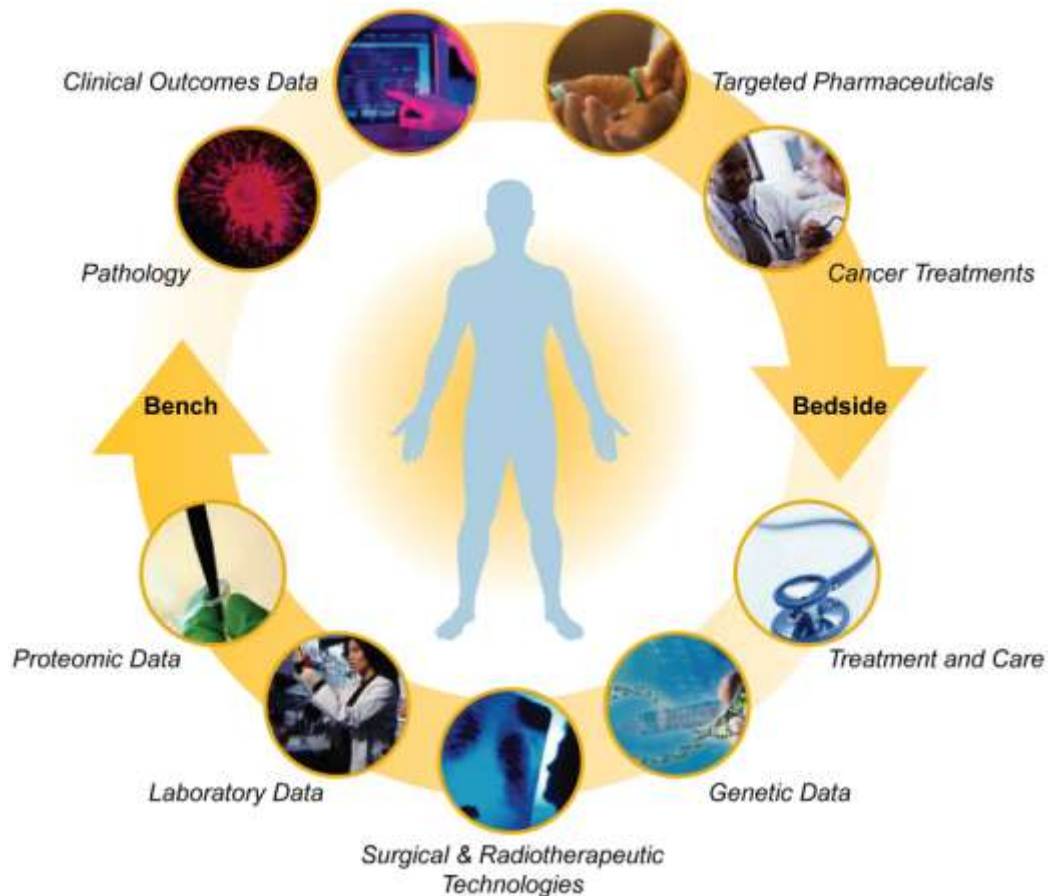
Building a Global Cancer Community

Ken Buetow, Ph.D.
Director,
Center for Biomedical Informatics and
Information Technology
National Cancer Institute

Biomedical Informatics Without Borders
Implementing Interoperability
June 21, 2010



21st Century Biomedicine



- **Personalized, Predictive, Preemptive, Participatory.....**
- **Unifies** discovery, clinical research, and clinical care (bench-bedside-bench) into a seamless continuum
- **Results** in improved clinical outcomes
- **Accelerates** the time from discovery to patient benefit
- **Embraces** the **Global** nature of cancer and the unique international insights in addressing its challenge
- **Enables** a **Learning Health System**,

Redefining Cancer at a Molecular Level





National Cancer Institute

U.S. National Institutes of Health | www.cancer.gov



CLINICAL PROTEOMIC TECHNOLOGIES for CANCER

Advancing Protein Science for Personalized Medicine



National Cancer Institute

U.S. National Institutes of Health | www.cancer.gov



CGEMS

Cancer Genetic Markers of Susceptibility

About CGEMS | News & Announcements | Resource Room



National Cancer Institute

U.S. National Institutes of Health | www.cancer.gov

NCI Alliance for Nanotechnology in Cancer

Developing Small Tools with a Big Impact on Cancer

Learn About Nanotechnology | Collaborate | Alliance in Action

NANOTECHNOLOGY HAS THE POTENTIAL TO FIGHT CANCER WHERE AND WHEN IT BEGINS.

LEARN MORE

Exploring Nanotechnology | Understanding the Potential

Watch a Video Journey Into the World of Nanotechnology in Cancer

Discover how nanotechnology is changing the way we understand and treat cancer

THE IMPACT OF NANOTECHNOLOGY



National Cancer Institute

U.S. National Institutes of Health | www.cancer.gov



TARGET

Therapeutically Applicable Research to Generate Effective Treatments

About TARGET | Areas of Research | Resources | Newsroom | Launch Data Portal

Promoting Discoveries Leading to Cures

What is TARGET? The Therapeutically Applicable Research to Generate Effective Treatments (TARGET) Initiative seeks to harness the power of modern genomics technologies to rapidly identify valid therapeutic targets in childhood cancers so that new, more effective treatments can be developed and ultimately bring new hope to children and their families who face the devastating burden of these diseases.

Learn more



National Human Genome Research Institute

Sign up for updates

Search GO

About TCGA | What We Do | Publications | News Center | Launch Data Portal

The Cancer Genome Atlas (TCGA) is a comprehensive and coordinated effort to understand the genetics of cancer using innovative technologies.

Cancer Bulletin Profile: Meet Dr. Raju Kucheralapati

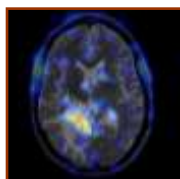




Enabling a rich, molecular definition of Cancer

Multiple forms of cancer

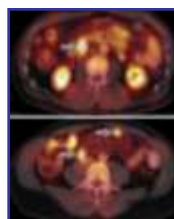
glioblastoma multiforme
(brain)



squamous carcinoma
(lung)



serous
cystadenocarcinoma
(ovarian)



(20 additional
types planned)

Multiple Organizations

Biospecimen Core
Resource

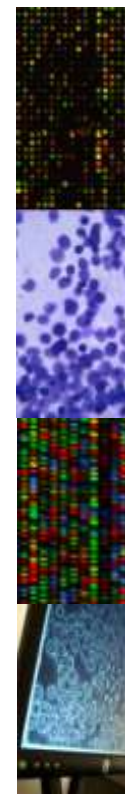
Cancer Genomic
Characterization
Centers

Genome
Sequencing
Centers

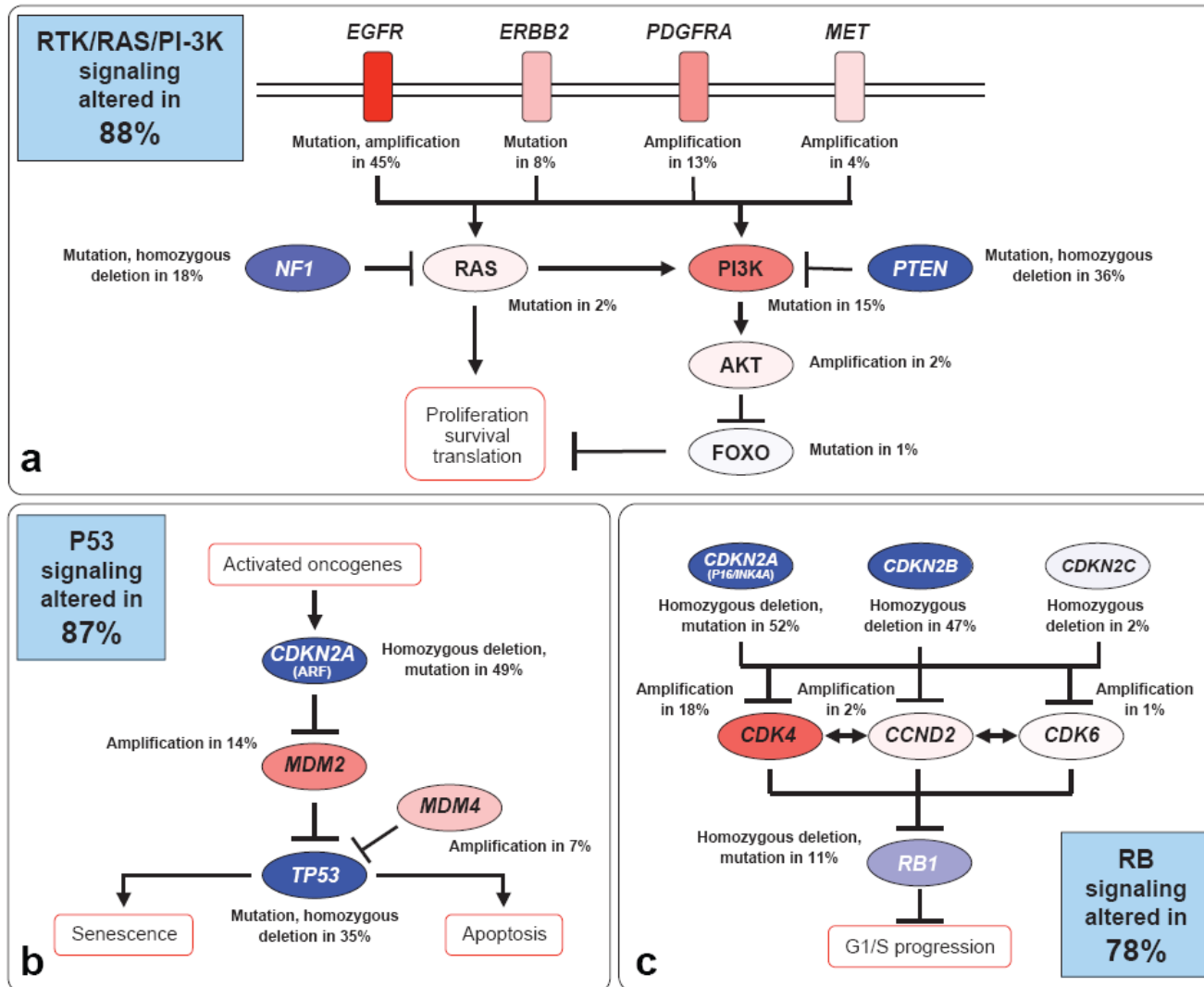
Genome Data
Analysis Centers

Multiple data types

- Clinical diagnosis
- Treatment history
- Histologic diagnosis
- Pathologic status
- Tissue anatomic site
- Surgical history
- Gene expression
- Chromosomal copy number
- Loss of heterozygosity
- Methylation patterns
- miRNA expression
- DNA sequence



GBM Results: Pathways



Patient selection for HER2 Tx required tissue screen and allowed only 1 of 4 women to participate



| Calculated Sample Size And Study Duration | Hypothetical HER2+ Prevalence | Required “Screened” Population |
|---|-------------------------------|--------------------------------|
| 1250 → 52 mos | 100% | 1250 |
| | 50% | 2500 |
| | 25% | 5000 |

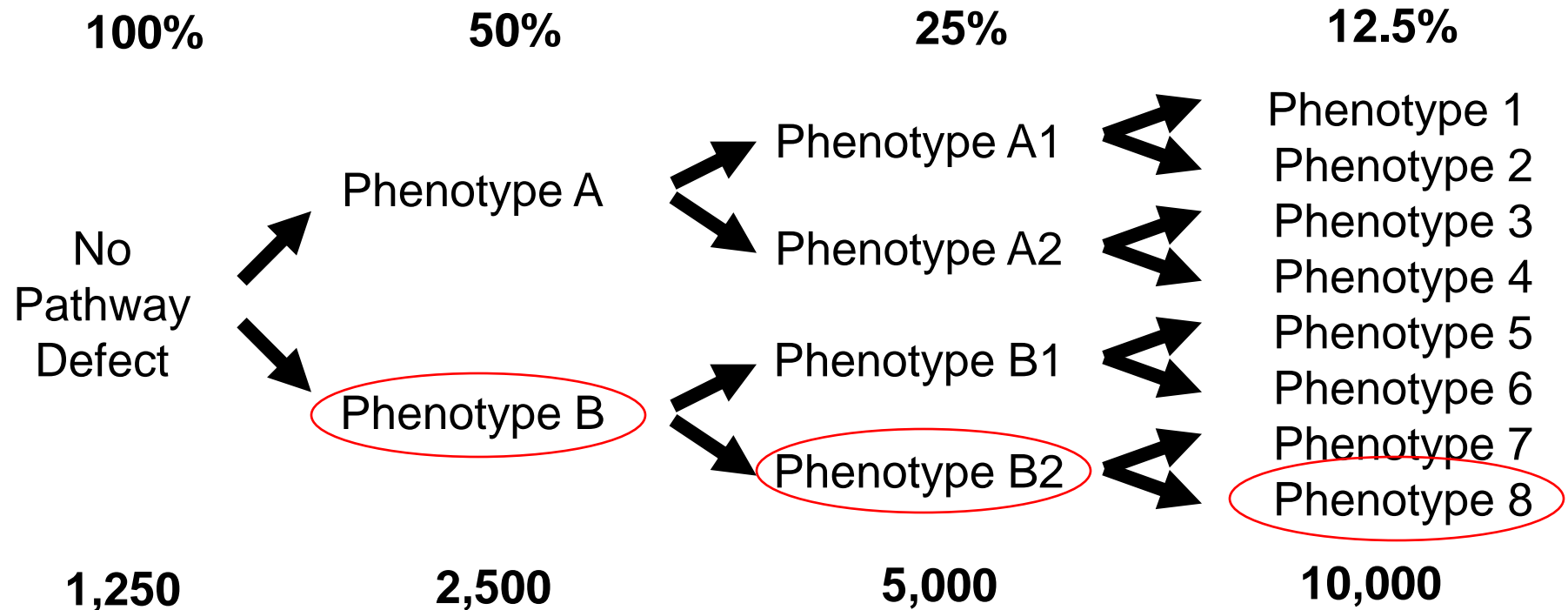
* Need to obtain a suitable specimen, wait for test results. (Results were obtained in days to weeks)

* Need to screen many patients.

Size of Population with Pathway to Inhibit*



Population fraction containing signature



Size of Population Needed To Screen

Courtesy H. Kim Lyerly, M.D., Director

20th Century Research > Care Paradigm



Discovery

- Biological pathways
- Target identification and validation

Product Development

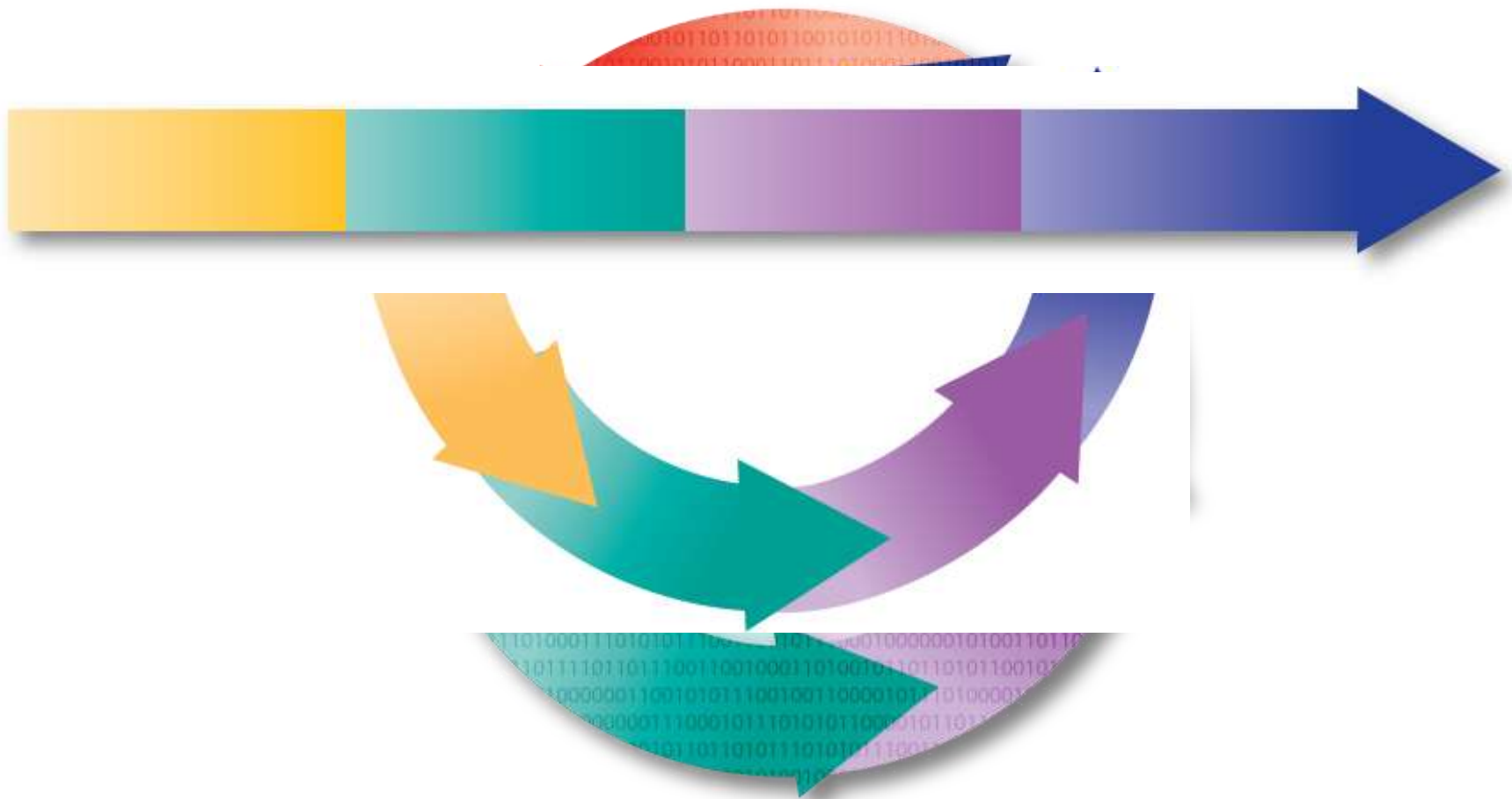
- Candidate selection and Optimization
- Pre-clinical testing
- Phase I, II, III
- New Drug application and Approval

Clinical Care

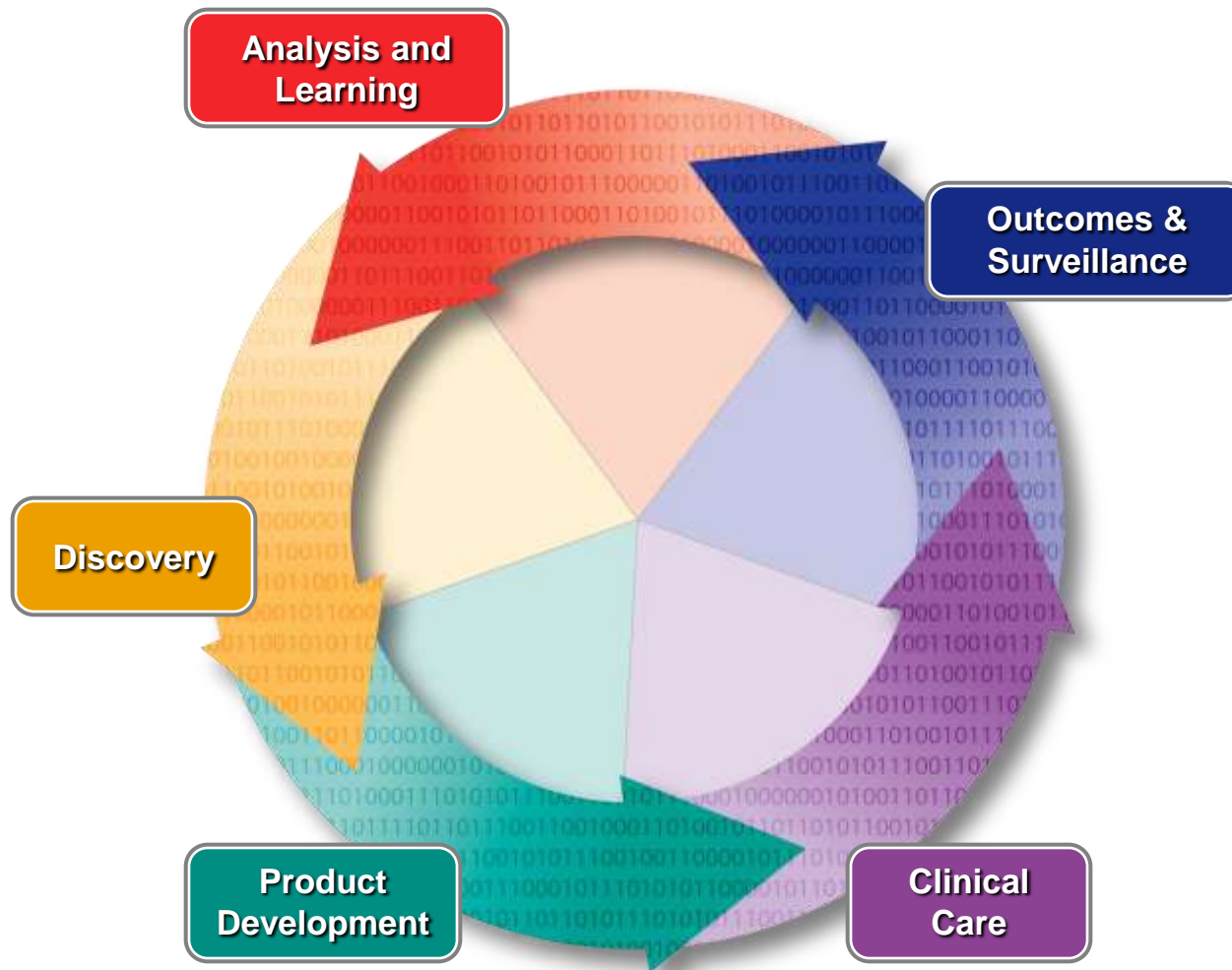
- Product launch
- Clinical adoption

Outcomes & Surveillance

- Reporting of serious/fatal ADRs
- Re-labeling (or recall) as needed
- Additional indications as warranted



21th Century Learning Health System



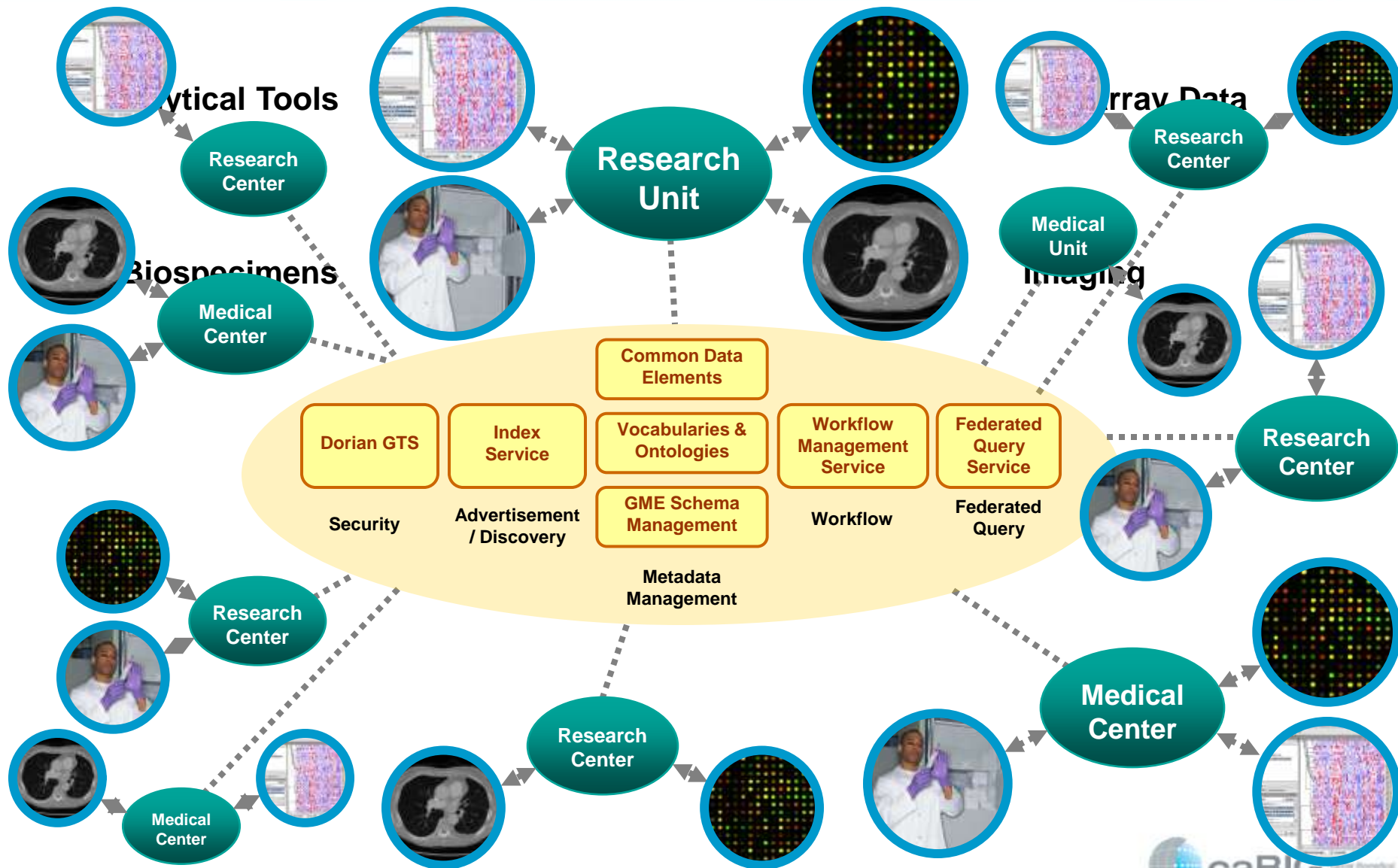
Challenges: The Biomedical Landscape



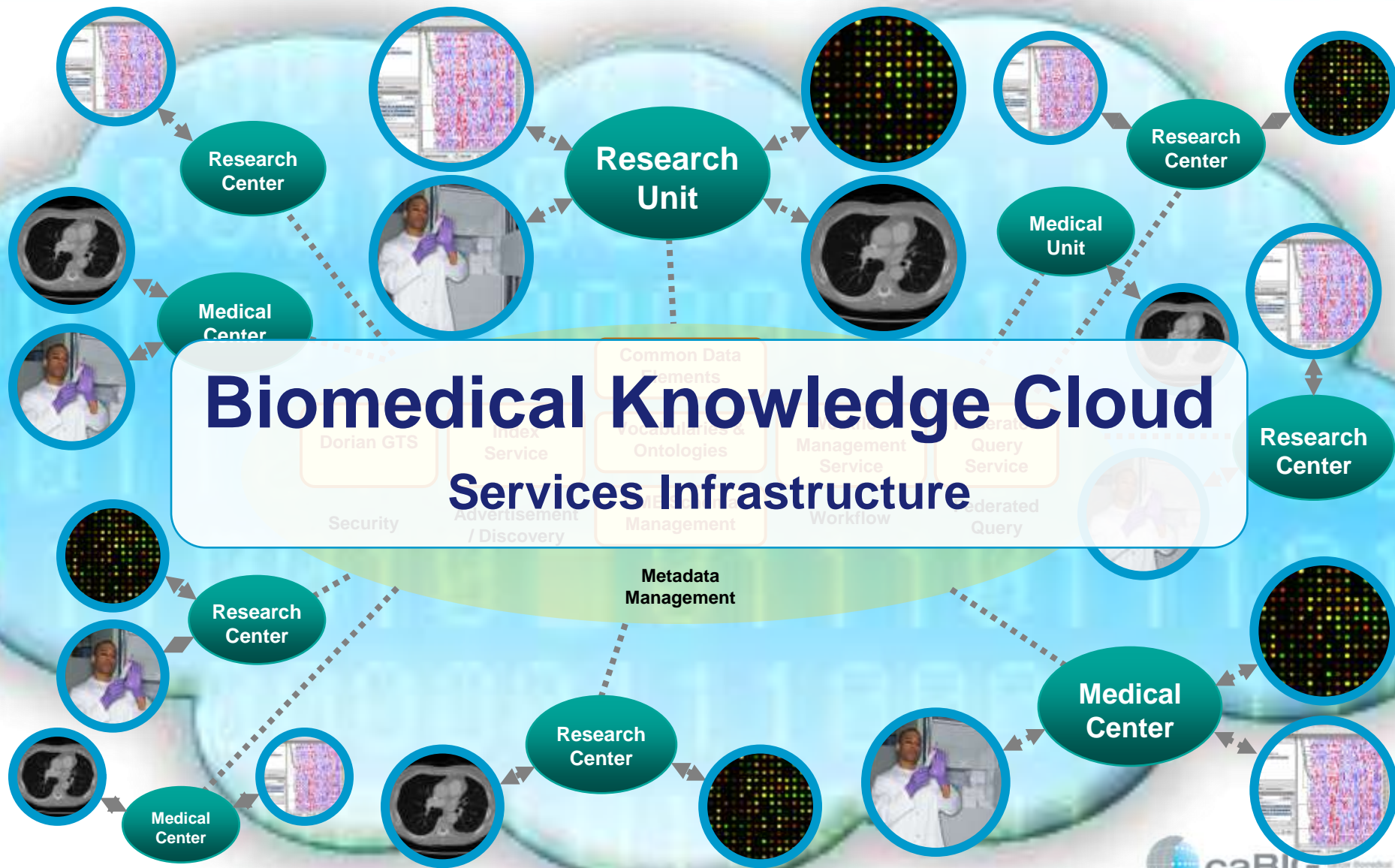
- **Isolated information “islands”**
- **Information dissemination uses models recognizable to Gutenberg**
- **Pioneered by Royal Academy of Science of London in the 17th century**
 - Write manuscripts
 - “Publish”
 - Exchange information at meetings



IT-enabled ecosystem



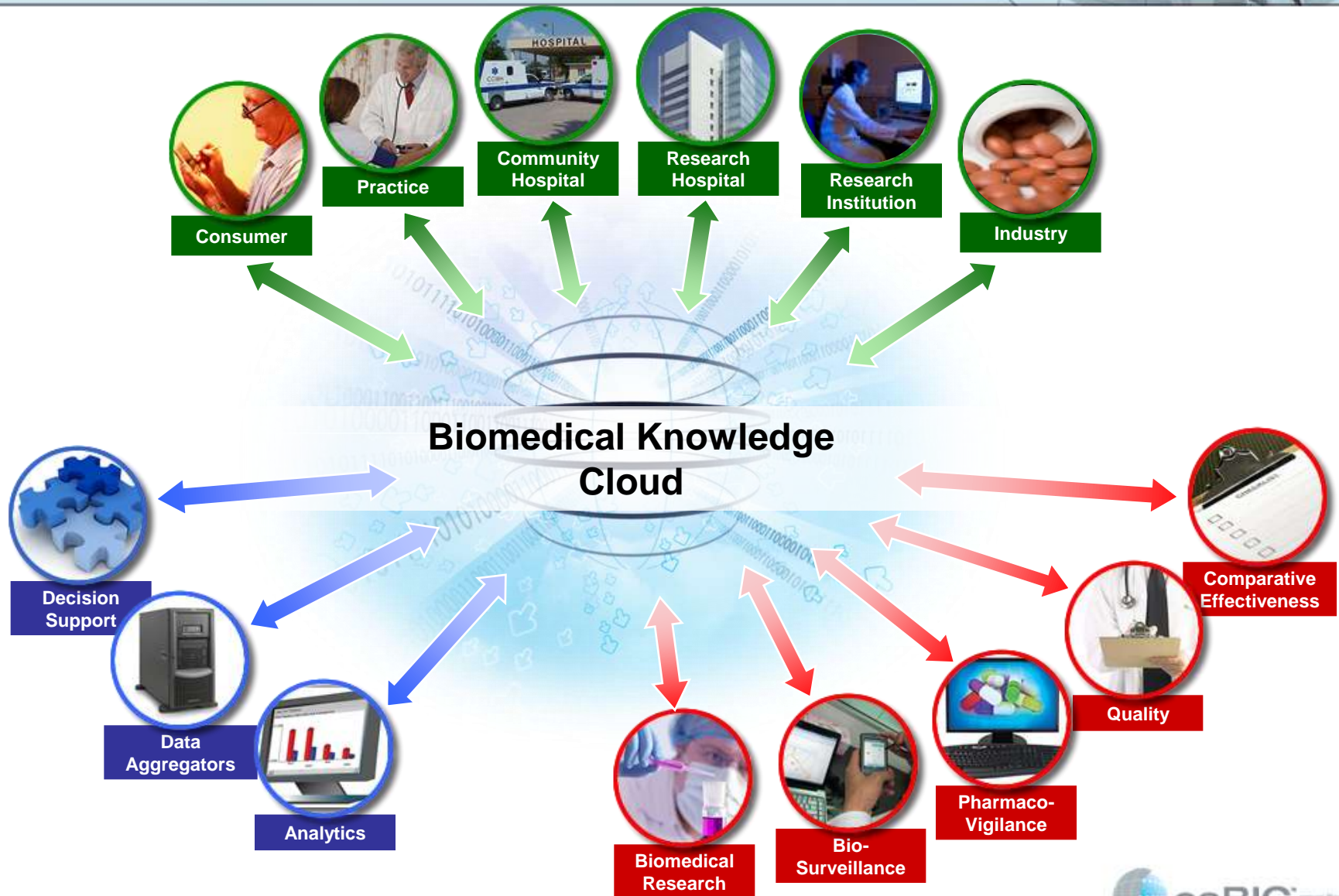
IT-enabled ecosystem



IT-enabled ecosystem



A 21st Century Biomedical Ecosystem

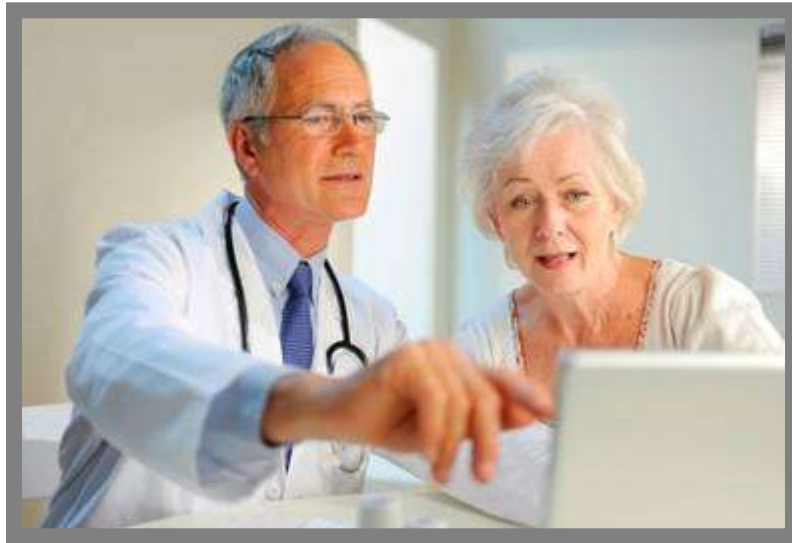


“Smart” Electronic Health Records



Oncology-extended EHRs enable tracking of cancer diagnostic and staging information, treatment plans, and patient outcomes

Oncology-extended EHR



Client Packet:

Client ID: SP040477F0 Name: SALLY PARKER DOB: 04/04/1977 AGE: 31
History: SP040477F0 - SALLY PAR... Show closed registrations: ☐ SSN: 395-98-3659 Phone: -

Registration

Registration Date: 09/17/2008 Closed: ☐
☐ Crisis Registration:
Referral Date: 09/17/2008 VALUEOPTIONS
RBHA: 05 MARICOPA RBHA

| Category | Value | As Of Date |
|---------------|-----------------------------|----------------|
| Managing | JILL JONES, MSW | 09/17/08 08:00 |
| Outpatient | 2 Agency office: 2 | 09/17/08 08:00 |
| Diagnosis | 291.81 ALCOHOLIC WITHDRAWAL | 09/17/08 08:00 |
| Program | Standard Intake - No Sub | 09/17/08 08:00 |
| Quar. Primary | UNITED BEHAVIORAL HEALTH | 09/17/08 08:00 |

Medical History:

- Enrollment Date: Sep 17 2008 09:57:00
- Client Status
- Client Program
- Agency FIF
- Comp. Assessment Part A (02/01/05)
- Comp. Assessment Part B and C (02/01/05)
- Comp. Assessment Part D
- Treatment Plan
- Consent - Report Only
- Magellan Demographic
- Magellan Enrollment (09/01/07)
- Magellan Assessment (09/01/07)
- Magellan Intake
- Lab Test
- MMI Psych Evaluation
- Chemotherapy drugs**

Buttons: Edit, Save, Cancel, New Registration, Interim Assessment, Closure, New Progress Note, Hide Notes, Referral, New Packet, Print Labels, Review Notes, Cancel

“Smart” Electronic Health Records



Web-based tools enable consumers/patients to record their personal information and treatment responses, linked into their EHRs



Family Health History



Personal Genomics

101010101



Patient-Reported Outcomes-enhanced EHR

| Category | Value | As Of Date |
|----------------|-----------------------------|----------------|
| Managing: | JILL JONES, MSW | 09/17/08 09:00 |
| OutPatient: | 2 Agency office: 2 | 09/17/08 09:00 |
| Diagnosis: | 291.81 ALCOHOLIC WITHDRAWAL | 09/17/08 09:00 |
| Program: | Standard Intake - No Sub | 09/17/08 09:00 |
| Guar. Primary: | UNITED BEHAVIORAL HEALTH | 02/01/09 09:00 |

☐ Client Packets

Client ID: SP040477F0 Name: SALLY PARKER DOB: 04/04/1977 AGE: 31
 History: SP040477F0 - SALLY PARKER Show closed registrations: ☐ SSN: 395-99-3659 Phone: --

Registration

Registration Date: 09/17/2008 Closed:
☐ Crisis Registration:
 Referral Date: 09/17/2008 VALUEOPTIONS --
 RBHA: 05 MICOPICA RBHA --

| Category | Value | As Of Date |
|----------------|-----------------------------|----------------|
| Managing: | JILL JONES, MSW | 09/17/08 00:00 |
| Op/Patient: | 2 Agency office: 2 | 09/17/08 00:00 |
| Diagnosis: | 291.81 ALCOHOLIC WITHDRAWAL | 09/17/08 00:00 |
| Program: | Standard Intake - No Sub | 09/17/08 00:00 |
| Guar: Primary: | UNITED BEHAVIORAL HEALTH | 02/01/09 00:00 |

FHH **BRCA 1**

Standard (By Form) (By Category) Current

New Registration **Interim Assessment** **Closure** **New Progress Note** **Hide Notes** **Referral**
New Packet **Print Labels** **Review Notes** **Cancel**

| Original Form | | Fast/Question/Variable | Description/Unit/Value Domain | Position | Group Comments | Relationship |
|---|--|---|---|--|--|--|
| Outcome Measures CRF Working Spreadsheet of Fields/Variables/Questions | | | | | | |
| Original Form | | Fast/Question/Variable | Description/Unit/Value Domain | Position | Group Comments | Relationship |
| «Last Contact» | | | | | | |
| 1 | COB 5045 | ACRN0302 F1 | What is the source of the last contact information? | Medical Record, Participant, Family, Site Physician, CRA, Cancer Registrar, Outside Physician/Hospital | Harmonized, conditional (grouto-driven) | This has an enumerated list of values (LOV) to be included in the value domain of the CDE. |
| 2 | ACRN0302 F1, COB045, Trans Sur, ECOG E3302, TREC 0423 F1 | Date of last contact | | Harmonized, conditional (grouto-driven) | | |
| 3 | «Last Contact» | | | | | |
| «Vital Status» | | | | | | |
| 4 | COB 2684 AC0000, Z001, ECOG E3302, ACRN0302 F1, RT00 0423 F1 | What is the vital status? | Participant's Vital Status | Dece, Alive, Lost to Follow-up and Unknown | Harmonized, conditional (regulatory issue) | Should be renamed to "Participant's Vital Status" |
| «Vital Status» | | | | | | |
| «Disease Status» | | | | | | |
| 5 | COG AMB1 0621 (Reporting Period), AMB10421, COG AMB1 0621 (Jump Alert) | Was disease status evaluated during the reporting period? | No, Yes | Harmonized conditional (grouto-driven) | | |

10101010101

Using EHRs to Empower Survivors



Clinical Information from EHRs can be fed electronically into the Personal Health Records

Smart EHR

Client Packets

Client ID: SP04047760 Name: SALLY PARKER DOB: 04/04/1977 AGE: 31
History: SP04047760 - SALLY PARKER Show closed registrations: ☐

Registration

Registration Date: 09/17/2008 Closed: ☐
Referral Date: 09/17/2008 VALUEOPTIONS
RBHA: 05 MARICOPA RBHA

| Category | Value | As Of Date |
|---------------|-----------------------------|----------------|
| Managing | JILL JONES, MD | 09/17/08 00:00 |
| Outpatient | 2 Agency office | 09/17/08 00:00 |
| Diagnosis | 291.81 ALCOHOLIC WITHDRAWAL | 09/17/08 00:00 |
| Program | Standard Intake - No Sub | 09/17/08 00:00 |
| Guard Primary | UNITED BEHAVIORAL HEALTH | 09/17/08 00:00 |

FHH BRCA 1

Chemotherapy drugs
Tumor genetic profile

10101010101

Personal Health Record

Ken's health information

Conditions

- Hypertension
- Diabetes
- Asthma

Medications

- Blood Glucose Measurement
- Blood Pressure Measurement
- Height Measurement
- Lab Test Results
- Peak Flow Measurement
- Weight Measurement

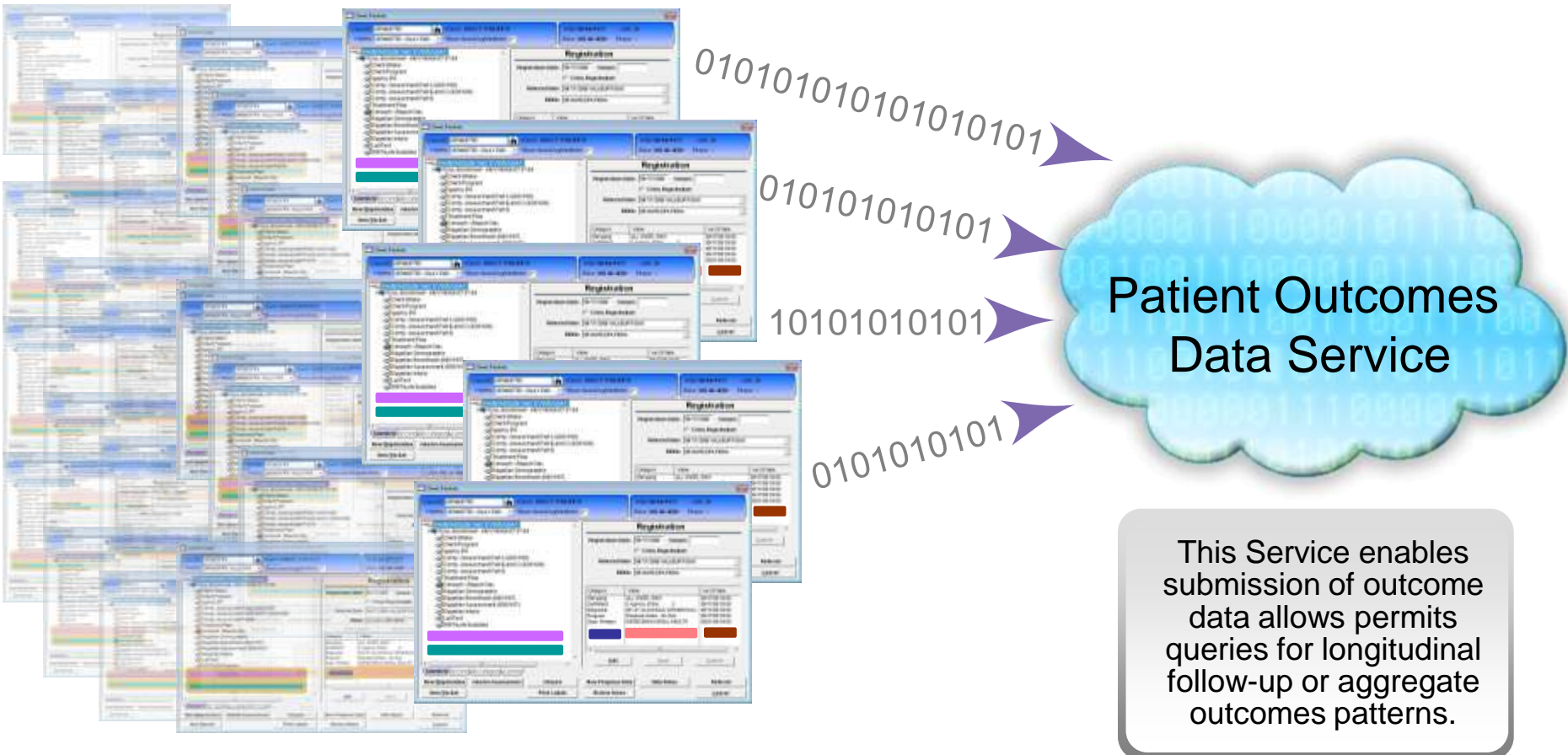
Actions

- Add a new item
- Upload a file
- New item
- Export information

Utilizing “Smart” Electronic Health Create a Learning Health System



With **appropriate authorization**, data on patient encounters can be electronically fed into a Patient Outcomes Data Service



All Stakeholders Benefit from the Patient Outcomes Data Service



Patient Outcomes
Data Service

Physicians

Individualizing
Clinical Care

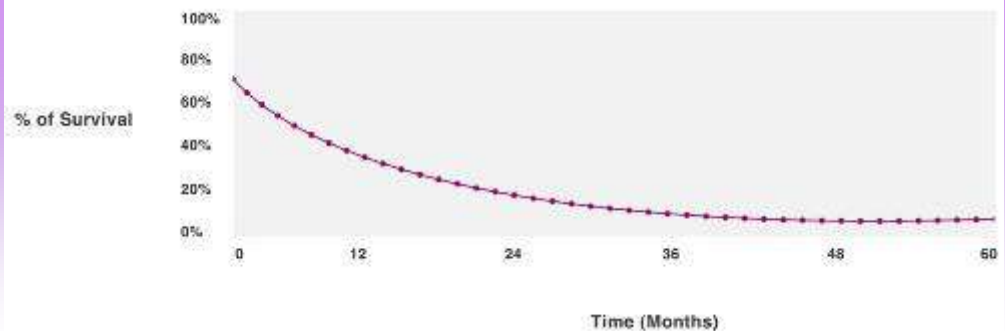
Clinical Decision
Support Tools

Comparisons
with other
patients

Alerts to
potential drug
interactions

Alerts to genetic
disease risks

Opportunities for
clinical trial
enrollment



All Stakeholders Benefit from the Patient Outcomes Data Service



Physicians

Individualizing
Clinical Care

Patients / Consumers

Understanding
my options

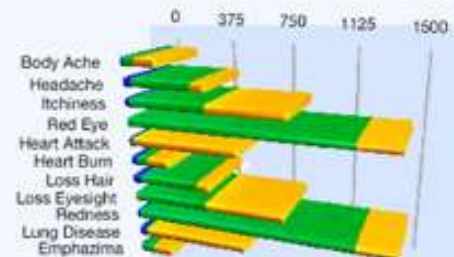
Patient Outcomes
Data Service

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How do I
compare
to others?

How do I get into
a clinical trial?

What should I
expect from
this treatment?



All Stakeholders Benefit from the Patient Outcomes Data Service



Patient Outcomes
Data Service

Physicians

Individualizing
Clinical Care

Patients / Consumers

Understanding
my options

Improving the
Healthcare System

Comparative
Effectiveness

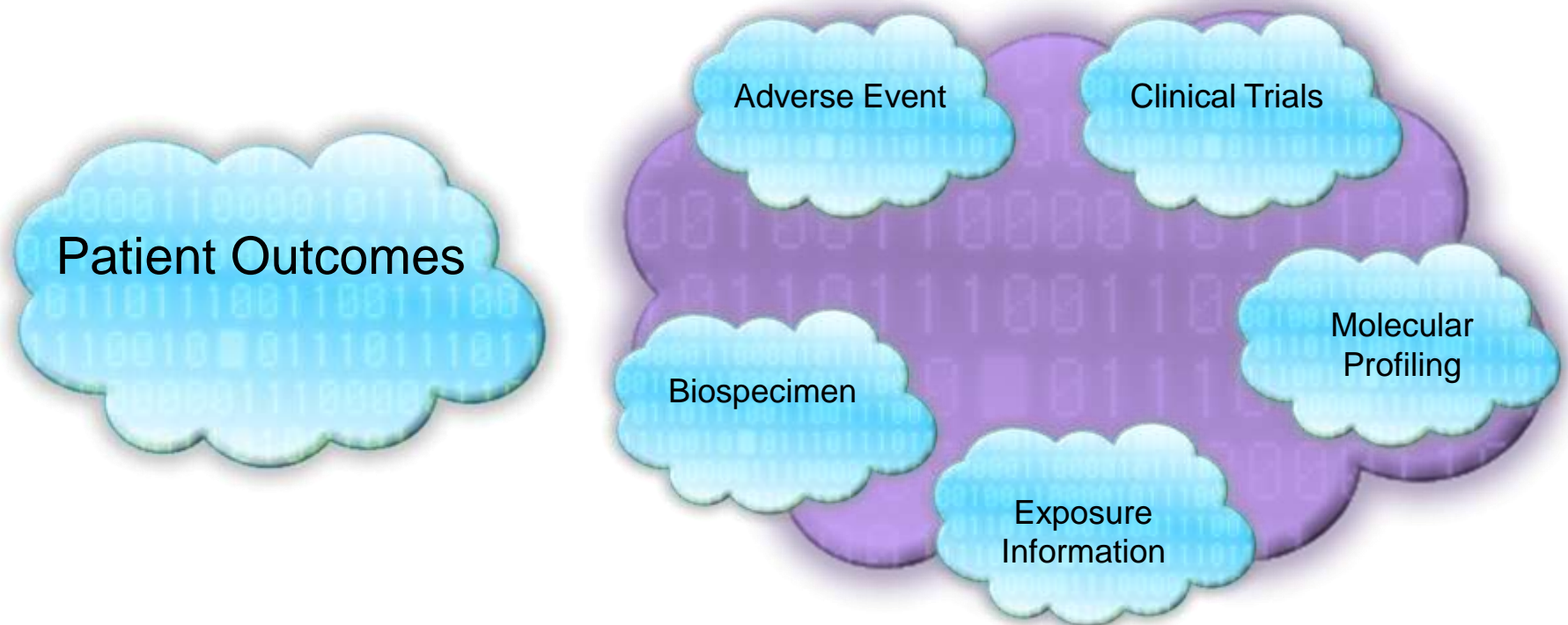
Quality

Pharmaco-
vigilance

The Patient Outcomes Resource Is One of Many within the Biomedical Community



Cancer Knowledge Cloud



Researchers Can Query the Data in the Cancer Knowledge Cloud



Cancer
Knowledge
Cloud

Epidemiologists

- Query data to seek correlations among genes, environment, outcome
- Develop standing online cohorts of volunteers

Basic Researchers

- Generate new hypotheses
- Identify biomarker-outcome correlations
- Validate biomarkers *in silico*

Clinical Researchers

- Seek clinical trial participants
- Enrich clinical studies with appropriate sub-groups
- Identify new indications

New Knowledge from Research Is Fed into the Cancer Knowledge Cloud



Cancer
Knowledge
Cloud

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Epidemiologists

New links to behaviors and exposures that increase / decrease risk of disease or disease reoccurrence

Basic Researchers

New drug targets

Clinical Researchers

Targeted drugs for molecularly-defined sub-groups

Virtuous Circle From Smart EHRs Through Research and Back to Clinical Care (Rapid Learning Healthcare System)



“Smart” EHRs



Cancer
Knowledge
Cloud

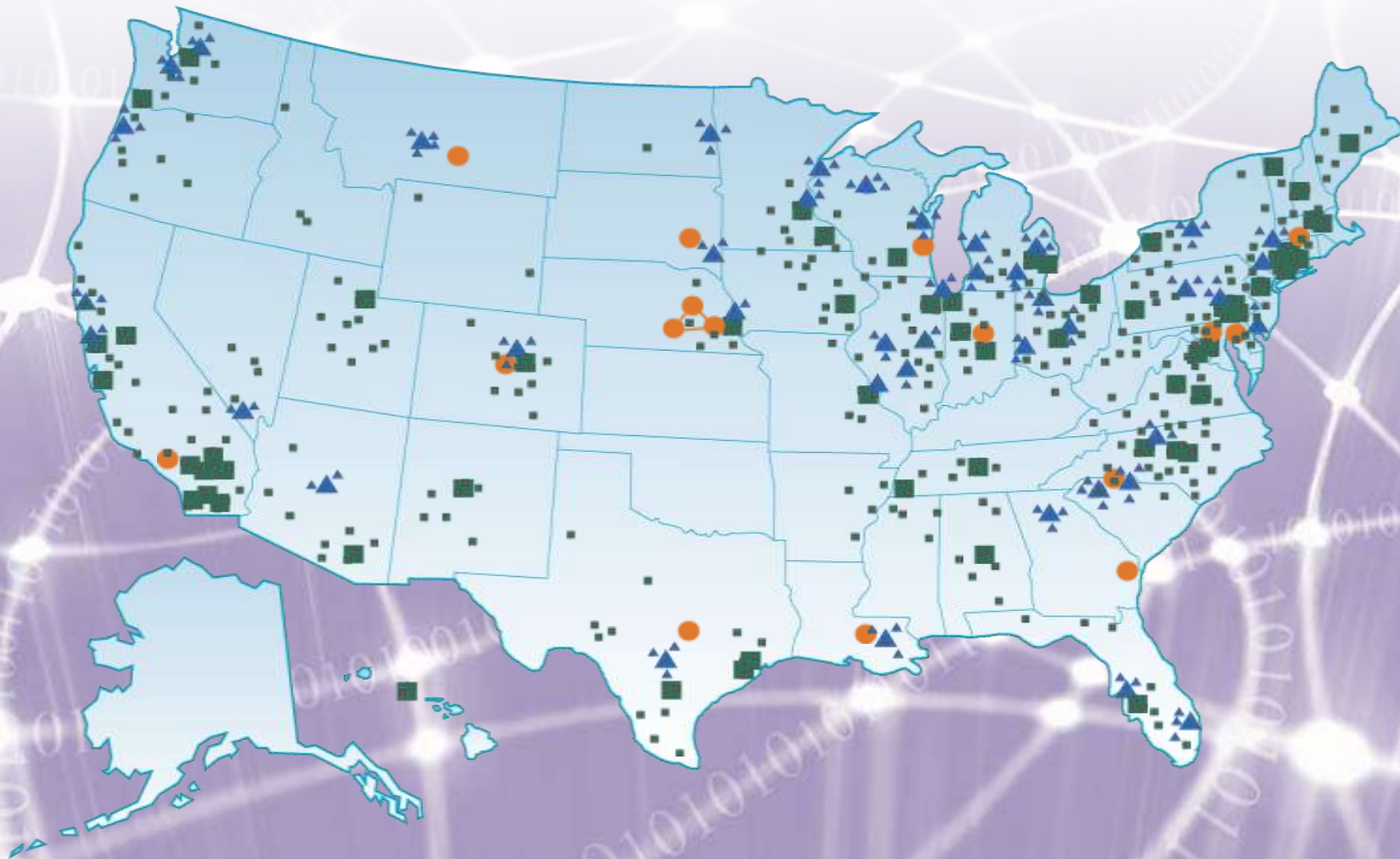


Researchers

Linking the Cancer Community: Nationally...



■ - NCI Designated Cancer Centers ● - NCI Community Cancer Center Program Sites ▲ - Community Oncology Practices



...and Around the Globe*



*(*United States, Mexico, Chile, Uruguay, Argentina, Brazil, U.K., Netherlands, Germany, Czech Republic, Finland, Jordan, Pakistan, India, China, Australia, New Zealand)*